



The Exceptional Advocate

A newsletter for military families with special needs

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Air Force Spouse of the Year Brings Disability Advocacy to the Forefront

Jeremy Hilton is not your average military spouse. To begin with, not only is he a rarity among the predominantly female population of military spouses, he's a United States Navy veteran, and graduate of the U.S. Air Force Academy who cross-commissioned to the Navy where he served as a submariner. Hilton is one of six military spouses vying to become the 2012 Military Spouse of the Year, a competition held by a magazine for military spouses. Spouses in the running for Military Spouse of the Year have each been nominated and selected for each Service branch. Hilton holds the title "2012 Air Force Spouse of the Year." Hilton makes it clear that, like many military spouses, he wears many "hats." He is a devout disability rights advocate for military families and has been working to influence policy at every level.

When the Hiltons' daughter, Kate, was born, she received an unexpected diagnosis of hydrocephalus, a condition that causes a buildup of fluid inside of the skull, which leads to swelling of the brain. Hilton and his wife, Renae, decided that he would end his Navy career to provide full-time care for their daughter while Renae continued to serve in the Air Force. Hilton makes it known that he is not fond of the term "stay-at-home dad." He feels the name doesn't quite give enough credit to the incredible amount of work done by parents who choose to stay at home to take care of their children.

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Respite Care Across the Services

The daily routines of taking care of a family member with a severe disability can take a physical and emotional toll on the primary caregiver, especially for family members requiring around-the-clock care. Respite provides a short-term break from caregiving activities allowing parents and caregivers to do things such as rest, run errands, spend personal time alone, or spend time with friends. A variety of options are available for respite care services, however, the availability varies within the Services.

Navy

The Navy allows families with children up to eighteen years of age who are enrolled in the Exceptional Family Member Program (EFMP) as Category IV or V (and their siblings) to receive up to forty hours of respite care per month at Navy installations in the following areas:

- Bremerton, WA
- Greater Washington, DC
- Jacksonville, FL
- Norfolk, VA
- San Diego, CA

Sponsors stationed at other Navy bases or on independent assignment are approved for respite care on a case-by-case basis. For more information about the Navy Respite Care Program or to apply for assistance, contact the local EFMP Manager or call Child Care Aware® at 1 (800) 424-2246.

Marine Corps

Families enrolled in the Marine Corps EFMP may receive up to forty hours of respite care per month, per family. For more information on the Marine Corps EFMP Respite Care Program or to apply for assistance, contact the local EFMP manager.

Army

Army leadership is committed to providing Soldiers and families a quality of life commensurate with their service, which includes families with special needs.

Eligibility for Army EFMP respite care services is based on EFMP enrollment and the exceptional family member's (EFM) severe chronic medical condition documented on the DD Form 2792 (Family Member Medical Summary). Qualifying families are eligible to receive up to forty hours of EFMP respite care monthly for each eligible EFM.

Army Community Service Family Support staff use the Family Services Needs Matrix to determine allowable hours.

EFMP respite care services are available Army-wide, regardless of where the Soldier and/or family member are located. For detailed information regarding respite care and other EFMP concerns, please go to [ARMY OneSource](#) or contact any local installation Army Community Service EFMP manager.

Air Force

The Air Force EFMP now offers respite care through a partnership with the [National Association of Child Care Resource & Referral Agencies](#) (NACCRRA). Air Force families who have children up to eighteen years of age diagnosed with moderate or severe special needs under the EFMP, specifically those with complex medical conditions, may be eligible to receive respite care. The program provides between eight and twenty hours of respite care per month based on the Airman's deployment status and the severity of exceptional family member's condition. Sibling care is now also available at no cost to the family.

The Air Force EFMP Respite Care Program is currently available at Air Force installations in the following areas:

- Charleston, SC
- Colorado Springs, CO
- Hampton, VA
- Honolulu, HI

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Military Spouse Appreciation Day

Military Spouse Appreciation Day is recognized every year on the Friday before Mother's Day to honor the contributions and sacrifices of military spouses. Military spouses play a vital role in maintaining family readiness, juggling the responsibilities of maintaining their households, raising their families, and often working outside of the home while their spouses serve our country. Military spouses accept the notion that frequent moves, deployments, training, and sometimes Permanent Change of Station (PCS) orders will separate their families more often than they would like, but they make the most of it.

Although Military Spouse Appreciation Day is only recognized one day a year, we encourage you to support your fellow spouses all year around; reach out to each other, especially those spouses in families where the service member is deployed. Don't forget to show appreciation for male military spouses as well.

The community of families with special needs can relate to the sometimes overwhelming demands of taking care of an exceptional family member's needs. Imagine how it feels to handle all of the responsibilities on your own. A little thoughtfulness goes a long way.

Ways to Show Appreciation to a Military Spouse

What better way to show your appreciation to the military spouses in your life than with an act of kindness? So, what can you do to show appreciation? Here are a few ideas:

- Offer to babysit the children for a few hours
- Plan a spouse's day out
- Send some baked goods or chocolate
- Make dinner for the spouse's family and deliver it to the home
- Offer to wash the car or mow the lawn
- Invite the spouse out for coffee
- Share a book that you have read and enjoyed
- Send an inspirational card or e-card
- Call a military spouse to just to say, "Happy Military Spouse Appreciation Day."
- Welcome new military spouses to the area

Spouses: Military Spouse Appreciation Day is your day. Be proud of all you do in support of your Soldier, Sailor, Airman, or Marine.

Thank you—and happy Military Spouse Appreciation Day!

Photo Credit: Steven Hooper, U.S. Army Garrison Humphreys





EFMP at your Service

Sensory Movie Night at Hurlburt Field

The Exceptional Family Member Program (EFMP) at Hurlburt Field in Florida hosts a quarterly Sensory Friendly Movie Night in partnership with the USO.

"What makes this a sensory event is the fact that we adjust the lighting and sound for those attending who may be uncomfortable otherwise. In addition, the families are given the freedom of a relaxing atmosphere where the kids don't have to sit still and don't have to be quiet. All who attend are understanding and accepting of the fact that some kids with special needs just can't do that. It makes it an enjoyable experience for everyone," says Ruthy Srun, EFMP-Family Support Coordinator at Hurlburt Field. Drinks, pizza, and popcorn make the event a total "dinner and movie" experience for families.

Four movie nights have been hosted since 2011. "Participation is never disappointing," says Srun. "We normally have between 50 and 120 family members there. At Hurlburt Field, we have an auditorium that used to be a base theater, so we are able to host the event there for free! All the families need is the desire to have fun. We also have an information table at the event where we offer information on upcoming events and community resources, so it is educational and fun!"

Some of the great feedback from parents included:

"Ruthy, thanks for a perfect movie night. It was just what we needed. Pizza was most perfect too! You are doing a great job." (Email)

"Thanks for the great night. We appreciate it so much. Cute movie." (Email)



"Thank you Hurlburt EFMP for movie night! This was our first event, my son had an amazing time, everyone was so friendly and all the kids were accepting of one another—very different atmosphere from school. We all had a wonderful time and were actually relaxed! Thank you." (Facebook Post)

It's a simple but great program and the families get nothing but enjoyment from the experience!

Call for Best Practices

Service Providers, do you have an event or best practice that you would like to share with our readers? If so, we want to hear about it.

What types of support groups or activities are you hosting for families in your community? Send us a description of your best program, tell us how it helps the community, and let us know the type of feedback you are receiving. Tell us what's working well. Your story could inspire other installation Exceptional Family Member Programs (EFMPs) to support families in new ways.

If your efforts are chosen to be highlighted in *The Exceptional Advocate*, we may contact you for more information and photographs. Submit your stories by clicking [here](#). In the subject line, type "EFMP Best Practices."

Note: The Office of Special Needs does not guarantee that your submission will be included in *The Exceptional Advocate*.

Employment Initiatives for Military Spouses

Military spouses in the job market know all too well how frequent relocations can impact their careers. According to the Military Spouse Employment Partnership (MSEP), one in every four military spouses is unemployed and looking for work. Employers, particularly in civilian communities, are sometimes hesitant to hire people associated with the military for fear that they may have to relocate after working for a short period of time. The costs associated with obtaining new licenses after moving to a new state can add up for spouses who require professional licenses.

Military spouse employment initiatives have been receiving much-needed attention for the past few years. Corporations are beginning to realize how much of an asset military spouses can be; and the growth of virtual employment opportunities has provided more flexible work options. In 2011, the Department of Defense (DoD) launched the expanded MSEP as part of ongoing initiatives

to improve career and educational opportunities for military spouses. MSEP connects companies that are actively hiring with military spouses who are seeking employment opportunities. Visit the [Military OneSource](#) MSEP information page to learn more.

Recommended Resources

Military OneSource Spouse Career Center (SCC)—provides education and career services, resources, guidance and consultations via telephone. Call Military OneSource at 1 (800) 342-9647 for more information.

Military Spouse Career Advancement Account (MyCAA)—provides tuition assistance for eligible military spouses and helps spouses train for portable careers. Visit [MyCAA](#) for more information.

Military Spouse Employment Partnership (MSEP) Career Portal—provides career resources, tips, and employment listings. Visit the [MSEP Career Portal](#) for more information.



Military Spouse Employment eMentoring—an online community for military spouses to receive personalized career guidance, advice, support, and inspiration from more experienced military spouses. “Corporate mentors” representing military-spouse-friendly firms also participate to assist spouses in seeking stable employment with an opportunity for upward mobility. MilSpouse eMentor is a partnership between AcademyWomen (a nonprofit organization promoting leadership programs and offering support for female graduates of the nation’s military academies’ officer development programs) and the U.S. Chamber of Commerce.

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- National Capital Region
- San Antonio, TX
- Tacoma, WA

Also, the Air Force is expanding its respite program to include the following installations in August 2012:

- Nellis, NV
- Creech, NV
- Scott, IL
- Hurlburt, FL
- Wright-Patterson, OH
- Elmendorf, AK
- Davis-Monthan, AZ

- Travis, CA
- Tinker, OK
- Shaw, SC
- Eglin, FL
- Offutt, NE
- Warner Robins, GA
- Moody, GA
- Minot, ND
- Fairchild, WA

Air Force Aid Society Respite Care Program

The Air Force Aid Society (AFAS) also provides needs-based assistance for Air Force families in need of respite

from normal care routines. The program is intended to assist families who do not have the means to pay for respite care. Assistance may be provided until the families can afford to pay for care, or until they are able to enroll in a military or community-based respite care program.

For more information about respite care for Air Force families, contact the installation EFMP Family Support Specialist or contact NACCRR’s Child Care Aware® toll-free at 1 (800) 424-2246.

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TRICARE® Q&A

Q: I think I may need professional help to cope with a behavioral health care issue; what should I do?

A: TRICARE recommends the following courses of action:

If it is an emergency, go directly to the closest emergency care or psychiatric health care facility. An emergency means that the physical well-being of an individual or those around him or her is at risk.

In the United States, you can call the National Suicide Prevention Lifeline at **1 (800) 273-TALK (8255)** or TTY: 1 (800) 799-4889. This hotline is a 24-hour, toll-free suicide prevention service available to anyone in suicidal crisis. You will be routed to the closest possible crisis center in your area. Your call is free and confidential.

Veterans living in the U.S. may call **1 (800) 273-TALK (8255)** and press “1” to reach the Department of Veterans Affairs (VA) hotline. This line is staffed by behavioral health professionals who work closely with local VA behavioral health care providers. *This number is not free of charge if dialed from outside the United States.*

If it's not an emergency, you should make an appointment for mental/behavioral health care. Since rules vary depending on the program enrollment type and your beneficiary category, you will need to follow the specific referral and prior authorization rules specific to your situation. Contacts for TRICARE mental health care are listed on the TRICARE website. You may also create a profile on the TRICARE website for accurate beneficiary information.

Content Source: TRICARE Management Activity

National Celiac Disease Awareness Month

May is National Celiac Disease Awareness Month. Celiac (pronounced SEE-lee-ak) disease is a condition that damages the lining of the small intestine and prevents it from absorbing nutrients in food. The damage is caused by a reaction from consuming gluten, a protein found in wheat, barley, and rye. While these ingredients are typically found in food such as bread, pasta, cookies, and pizza crust, gluten is also found in products that we use every day such as medicines, vitamins, and lip balms.

Anemia, infertility, weak and brittle bones, an itchy skin rash, and other health problems can arise

over time due to celiac disease. Symptoms of celiac disease vary from person to person. Symptoms include, stomach pain, gas, diarrhea, weight loss, and changes in mood. Because celiac disease has similar symptoms as other disorders, it can sometimes go undiagnosed. There is no cure for celiac disease; however, a gluten-free diet will help heal the intestinal lining over time.

Some fast facts about celiac disease include:

- The disease can develop at any point in life, from infancy to late adulthood.

- People who have a family history of celiac disease are at greater risk for developing it.
- As many as two million Americans may have celiac disease, but most don't know they have it.
- Celiac disease is diagnosed with a blood test and a biopsy.
- Visit the [National Institutes of Health](#) website for more information.

Content Source: National Institutes of Health and National Digestive Diseases Information Clearinghouse (NDDIC), a service of the National Institute of Diabetes and Digestive and Kidney Diseases.

Kid's corner

Here's an activity your kids can do to show just how special Mom is.

Kids: Draw a picture of yourself with your Mom in the picture frame below.

Decorate the picture frame by coloring it, adding stickers, or glitter to decorate it just the way you like it. Fill in the blank below about your Mom. When you are finished you can give it to your Mom for Mother's Day.



I love you because _____

TRICARE® Extended Care Health Option and Extended Care Health Option Respite Benefit

The TRICARE Extended Care Health Option (ECHO) is another possible solution for respite care. Under ECHO respite care services, a maximum of sixteen hours per month is allowed for any month as long as a family member is receiving other authorized ECHO benefits.

Those who qualify may be eligible to receive ECHO Extended Care Health Option (EHHC) respite care which provides up to forty hours per week (eight hours per day, five days per week) for families with homebound beneficiaries who have medical conditions requiring frequent interventions by a primary caregiver.

However, only one benefit, the ECHO or EHHC respite care benefit, can be used in the same calendar month, they cannot be used together. The allowances for EHHC respite care benefits are not cumulative and these benefits cannot be used as babysitting/child care services; for sibling-care; nor to enable employment, deployment, or the pursuit of education. TRICARE ECHO and EHHC respite care benefits are only available in the fifty states, the District of Columbia, Guam, Puerto Rico, and the U.S. Virgin Islands. Visit the [TRICARE](#) website for more information.

Note: Rules and restrictions for respite care vary between programs and the Services. Contact the installation EFMP for local information and program availability.

Content Source: TRICARE Management Activity

Spotlight on: Mental Health Awareness

May is Mental Health Awareness Month, the designated month to raise awareness about the importance of mental health and to help reduce the stigma associated with mental illness through education and outreach.

Although mental health professionals define mental illness and mental health differently, it is important to know that, if left untreated, mental illness may result in extensive problems and lead to dysfunction in many areas of a person's life. If you or someone you know is suffering from depression, anxiety, or other mental distress, take action by talking to a medical professional.

Mental health is a "state of well-being" that encompasses emotional, psychological, and social aspects of a person's life. According to the Centers for Disease Control and Prevention (CDC), positive mental health is associated with improved health outcomes.

Recommended Resources

If you need assistance with improving your overall well-being, or just need some guidance for dealing with the stressors of military family life, resources are available:

Military OneSource Health and Wellness Coaching Programs—a free resource for eligible individuals whose goal is to improve their health and

overall well-being. Sessions are conducted online or via telephone. Areas of focus for coaching include weight management, fitness and nutrition, health condition management, and stress management. Coaching is also available to address transitions such as lifestyle changes, deployment, moving, becoming a new parent, or retirement. Visit [Military OneSource](#) for more information.

Military OneSource Specialty Consultations—provides one hour consultations, up to twelve times a year, with a Special Needs Specialty Consultant. The consultant will assess your family's needs and answer your questions about moving benefits, education, finances, housing, support groups, medical resources, and more. To schedule a consultation, call Military OneSource at 1 (800) 342-9647 and ask for an appointment with a Special Needs Specialty Consultant.

Substance Abuse and Mental Health Services Administration (SAMHSA)—a comprehensive resource for information and support related to substance abuse and mental health services; as well as information about programs and initiatives to reduce the impact of substance abuse and mental illness on America's communities. Visit [SAMHSA](#) for more information.

Content Source: Centers for Disease Control and Prevention, National Institute of Mental Health, and Military OneSource.

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For the first six years of Kate's life, Hilton says it was all about survival as Kate had nine different surgeries. He says he served as his daughter's case manager and primary therapist, often working with Early Intervention Services (EIS), and doing the hands-on daily routines until she learned to walk at age five. The Hiltons researched tirelessly and did everything they needed to do to get Kate as far along as they possibly could, he says. It wasn't until Kate started school that Hilton was able to expand his advocacy role on a larger basis.

"The advocacy role is what drives me now, and it keeps me engaged on a level that I like," says Hilton. "I enjoy doing this." Hilton notes that many of the disability advocates he works with are parents who also happen to be veterans. "We really believe strongly that we may not be fixing the problem for ourselves, but we have some of the programs and services [now] because of some of the people who came before us. So we have some obligation," Hilton stated. Hilton says he has "seen where systems fall down. We don't want the people who come after us to have to deal with those same problems." Hilton continued, "So when the E3 becomes an E6, there may be better services in place."

If his drive and motivation are any indication, Hilton is a force to be reckoned with. It all started during a four-and-a-half-year period when the Hiltons got the first-hand experience of what it was like to do a Permanent Change of Station (PCS) move with a child who has a disability. At the time Hilton felt there was very little support for Air Force families with disabilities during the PCS process, and learned other parents felt the same. Through his involvement with programs like Specialized Training of Military Parents (STOMP), Hilton noticed disparities between the supports and services being offered in other branches of the military.

In Hilton's opinion, the Air Force was "getting left out in left field."

As a result of Hilton's efforts to draw attention about the "systematic problems," there have been a number of improvements made within the Air Force Exceptional Family Member Program (EFMP). "Sometimes you have to shock the system. Sometimes you have to find a way to be a 'squeaky wheel' and that doesn't come naturally to a lot of military families, but sometimes it's necessary," Hilton says. His advocacy role has expanded into three major pieces: TRICARE, Special Education, and Medicaid Waivers. He also encourages a holistic view of the system.

Hilton says he would change the Medicaid waiver system if he had the power. "This system is going to be what most of our families rely upon for support, particularly after a service member retires," Hilton said. From a family's perspective, it's what we worry about most."

Medicaid waivers pay for services for people with developmental disabilities using state and federal funds. States have different policies for Medicaid waivers and waiting lists to be eligible to use the funds can be years long. Individuals with disabilities who have lived in the same state through adulthood will be able to access funding for services much sooner than others who have not resided continuously in one state. Hilton offered the scenario of a service member who settles down in another state after retiring. By the time they retire, Hilton says, they may have a twenty-three-year-old child with a disability who is no longer eligible for the Extended Care Health Option (ECHO) and is now at the bottom of the waiting list for Medicaid waivers in that state. "We need to make sure that military children and spouses aren't disadvantaged because of our military service," he continues.

"My focus will always be disability issues," says Hilton, but he is hopeful

that he will be able to work on overarching military family issues as well. "We [the community of military families with disabilities] don't want to be forgotten." Hilton recalls the slogan of an earlier era of disability rights activists, "Nothing about us without us!" The slogan was used to communicate that groups affected by a policy should have full and direct participation in the policy-making process. The way Hilton sees things, it's necessary to interject whenever possible. "As we go forward, it's our job as advocates to provide feedback; to put pressure on things that we think our families need," says Hilton. "There are issues that still need to be worked on."

Hilton was nominated for Air Force Spouse of the Year by his wife and was selected through an online vote-based process. He is among the six finalists now running for Military Spouse of the Year, and says all of the spouses are equally deserving of the title. Each of the other Services also has selected a Spouse of the Year:

- Army Spouse of the Year—El Brown
- Navy Spouse of the Year—Erin Strasburger
- Marine Corps Spouse of the Year—Stephanie Geraghty
- Coast Guard Spouse of the Year—Jennifer Bassett
- National Guard Spouse of the Year—Christine Gilbreath

This year's winner of the overall Military Spouse of the Year will be announced on May 10 at an awards ceremony and luncheon in Washington, D.C. Hilton says being chosen as Military Spouse of the Year would help him bring more attention to important issues that affect military families with special needs and disabilities.

Jeremy Hilton resides in Burke, Virginia, with his wife, Renae, and their children, Kate, age seven, and Jackson, age two.



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Exceptional Family Member Program



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